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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

Establishment of the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children

AGENCY: Health Resources and Services Administration, HHS.

ACTION: Proposed Establishment of Discretionary Advisory Committee on Heritable Disorders in Newborns and Children.

SUMMARY: The U. S. Department of Health and Human Services announces establishment of the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children.

FOR FURTHER INFORMATION CONTACT: Debi Sarkar, Public Health Analyst, Health Resources and Services Administration, Maternal and Child Health Bureau; telephone: 301-443-1080; email: dsarkar@hrsa.gov.

SUPPLEMENTARY INFORMATION: Under the Public Health Service Act (PHS), 42 U.S.C. 217a, the Secretary of Health and Human Services directed that the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children shall be established within the Department of Health and Human Services (HHS). To comply with the authorizing directive and guidelines under the Federal Advisory Committee Act (FACA), a charter will be filed with the Committee Management Secretariat in the General Services Administration (GSA), the appropriate committees in the Senate and U.S. House of Representatives, and the Library of Congress to establish the Committee as a discretionary federal advisory committee.

Objectives and Scope of Activities. The purpose of the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children (DACHDNC) is to advise the Secretary of Health and Human Services about aspects of newborn and childhood screening and technical information for the development of policies and priorities that will enhance the ability of the state and local health agencies to provide for newborn and child screening, counseling and health care services for newborns and children having, or at risk for, heritable disorders. The DACHDNC will review and report regularly on newborn and childhood screening practices, recommend improvements for newborn and childhood screening programs, as well as fulfill the list of requirements stated in the original authorizing legislation.

Membership and Designation. The Committee shall consist of up to fifteen (15) voting members, including the Chair. The members of the Committee shall be appointed by the Secretary or his/her designee. Membership will be composed of the Chair, Special Government Employees (SGEs), and federal ex-officio members. Federal ex-officio members shall include the Administrator of the Health Resources and Services Administration; the Directors of the Centers for Disease Control and Prevention; the National Institutes of Health; the Agency for Healthcare Research and Quality; and the Commissioner of the Food and Drug Administration – or their designees. The Chair and other members shall be (a) medical, technical, public health or scientific professionals with special expertise in the field of heritable disorders or in providing screening, counseling, testing, or specialty services for newborns and children at risk for heritable disorders; (b) experts in ethics and heritable disorders who have worked and published material in the area of public health and genetic conditions; and (c) members from the public

sector who have expertise, either professional or personal, about or concerning heritable disorders in order to achieve a fairly balanced membership.

Administrative Management and Support. HHS will provide funding and administrative support for the Committee to the extent permitted by law within existing appropriations. Management and oversight for support services provided to the Committee will be the responsibility of the Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB).

A copy of the Committee charter will be made available through access to the FACA database, maintained by the GSA Committee Management Secretariat, or from the designated contacts. The website for the FACA database is <http://fido.gov/facadatabase/>.

AUTHORITY: The Discretionary Advisory Committee on Heritable Disorders in Newborns and Children is authorized in accordance with the Public Health Service Act (PHS), 42 U.S.C. Sec. 222 [217a]: Advisory councils or committees. The Committee is governed by provisions of Public Law 92-463, as amended, (5 U.S.C. App.), which sets forth standards for the formation and use of advisory committees.

Dated: April 16, 2013

Mary K. Wakefield

Administrator

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